

**PEER ACTION DISABILITY SUPPORT:
STATEMENT ON MENTAL HEALTH AND DISABILITY SERVICES
REDESIGN**

September 16, 2011

Good morning. My name is Bob Cihla, and I am President of PADS]. PADS is a grassroots organization that has been working since 2003 to improve the lives of people with disabilities in Linn County through peer support and community activism. We fight for respect for people with disabilities and for their place at the table when policies are being shaped which affect their lives. And that is why we want to thank you, Director Palmer, and also the legislators overseeing the redesign process, for reaching out to all stakeholders to hear our ideas and concerns. The most important thing you can do is to listen to Iowans with disabilities – really listen, at every stage of the Redesign process.

The following are critical to best practices, and we urge the Redesign Work Groups to make use of these common-sense suggestions:

- 1. It is our experience that no two people are exactly alike – even with the same diagnosis. Therefore, it is the position of P.A.D.S. to support a system that creates individualized budgets and individualized service plans that change as one's needs change. For example, one of our members has a developmental disability but not an intellectual one. She thinks accessing the ID Waiver would be great but only if her needs are understood and her desires are respected. She doesn't need or want supervision, or services to improve her cognitive functioning, or other services to address ID. Will Iowa's new service system empower consumers like her?**

2. *We need to bring Iowa into full compliance with Olmstead principles. The Olmstead Decision requires RESPECT for the abilities, skills, talents, and the potential of every individual, and the sheer right of every person with a disability to live, work and play in a community with the supports they need. P.A.D.S. wants the Redesign to make this principle a reality.* Right now, what you get depends on what kind of disability you have, not what your needs are or how much at risk you are of being put in an institution. Adults with physical disabilities, or people with DD who do not have a diagnosis of intellectual disability, have a very hard time getting the services they need, especially now that counties are facing such severe budget problems. Hundreds of people in these groups are in nursing homes. Only Iowans with mental illness or intellectual disability *have* to be served by counties, and only people with certain diagnoses can get access to the waivers. This is in direct conflict with *Olmstead*.
3. *The redesigned system has to address more than the traditional DHS services.* The Legislature and DHS need to consider how to incorporate housing and transportation into the mix, if people are going to be able to have real choices about where they live and what they're going to be able to do during the day. PADS has been working hard for years to improve public transportation. We have become educated advocates on the issue and have built some fine partnerships with county transit staff. We need a responsive system with extended operating hours that allow people to get to and from work, meetings, and other community activities after 5:00. Many people with disabilities need help with transportation costs. Is there a way to provide communities with grants to help pay those costs?

4. *Steps need to be taken to improve Non-Emergency Medical Transportation for Medicaid members.* Brokerage services need to be strengthened and made more consistent and easier to use. We need to make sure that Medicaid waiver participants (and *all* Medicaid members) know about, and know how to utilize the brokerage for ALL health care appointments. We need to educate case managers and waiver clients that transportation can be included in their service plans to get basic mobility needs met—and that these precious transportation units should not be used for medical appointments just because it's easier than going through the brokerage.
5. *We need a mental health and disability service system that is focused on keeping us at home with the supports we need.* Most people with disabilities have a real fear of ending up in a nursing home, and some of us with mental illness or other disabilities are having our services cut. One PADS member says: “They cut back my hours, but my disability didn’t change.” It may not seem like a big deal to cut someone’s homemaker services from three hours to two, but maybe you should ask that consumer first what that means in her life. As an example, because there’s a waiting line for the washing machines in her apartment building, her support worker might not be able to finish her laundry for her. So then, even though she has balance problems, she has to stand up from her wheelchair to reach for her wet laundry. For want of one hour of personal support, she is suddenly put in peril of falling, broking a hip and ending up in a nursing home. She doesn’t need much support, but without that support she is at personal risk and her services may end up costing the state of Iowa much more.

6. *We need a service system that meets the continuum of our needs.* In the words of one PADS member, “They need to fill in the cracks.” A number of PADS members have good days and bad days with their health, their level of pain, and their ability to handle daily life. One day they need a wheelchair to get down the street. The next they get along fine with a cane. That doesn’t mean you should take away their wheelchair. We don’t think people’s needs are completely and accurately assessed—we have seen too many snap judgments, too little information shared by case workers about how those decisions were made, and too many holes in the service system.
7. *The best source of support and information for people with disabilities is their peers.* *Peer support services should be expanded.* We applaud the Department of Human Services for developing reimbursement mechanisms for peer support for mental health recovery. PADS members have lived experience with mental illness, intellectual and developmental disabilities, physical and sensory disabilities—often co-occurring. We urge you to explore the benefits of peer support by people with similar co-occurring disability experiences, such as people with spinal cord injuries dealing with depression.

Thank you for your hard work planning a service system responsive to our needs and goals. We are strong, resilient and capable of making choices, taking responsibility for our lives, and contributing to society. But our needs can be complex and can change over time in ways we can’t control. What the Department, the Work Groups, and Iowa legislators do matters a lot. The decisions you make can be a matter of life and death for us.